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Communication, perception, and use of personalized side-effect risks in prostate cancer treatment-decision making: An observational and interview study

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ABSTRACT

Objective: We investigated how healthcare professionals (HPs) communicate personalized risks of treatment side-effects to patients with localized prostate cancer during consultations, and explored how these patients perceive and use such risks during treatment decision-making.

Methods: Patient consultations with nurse practitioners and urologists discussing personalized risks of urinary incontinence after prostatectomy were audiotaped, transcribed, and coded. Patients (n = 27) were then interviewed to explore their perceptions and use of personalized side-effect risks.

Results: HPs explained personalized risks by discussing risk factors, which was appreciated and recalled by patients. Personalized risks were typically communicated both numerically and verbally (70%). When using numbers, HPs always used percentages, but rarely used natural frequencies (14%). Uncertainty was disclosed in only 34% of consultations. One-third of patients used personalized risks in their treatment decision-making by either switching to another treatment or sticking to their initial preference.

Conclusions: Patients value and use personalized side-effect risks during treatment decision-making. Clearly explaining the relationship between risk factors and personalized risk estimates may help patients understand and recall those.

Practice implications

HPs should not only give patients specific and precise numerical risk information, but should also put effort in explaining how the personalized side-effect risks are determined.

1. Introduction

Men newly diagnosed with localized prostate cancer (PCa) are facing difficult decisions regarding treatment. They need to choose from a range of options including robot-assisted radical prostatectomy (RARP), external beam radiotherapy, brachytherapy, or active surveillance [1],

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which have equivalent survival outcomes but differ in the risks of side-effect [2,3]. For instance, RARP is associated with urinary incontinence and radiotherapy with bowel problems, which can have a serious negative effect on PCa survivors [4]. It is therefore important that patients are well informed about treatment side-effect risks during the shared decision-making (SDM) process [5]. Numerical risks (e.g., probabilities that patients will experience any adverse event) are ideally communicated by the urologists and/or nurse practitioners (NPs) during a consultation and in tools such as patient decision aids [6]. However, these risks are typically generic and based on the "average patient", which makes it difficult for patients to understand and translate those risks to their individual situation [7–10].

In light of the growing emphasis on personalized healthcare and outcome probabilities in clinical practice during SDM [11,12], it has become more feasible to provide patients with *personalized risk of* treatment outcomes such as side-effects [13]. These personalized risks take into account patient (e.g., age) and clinical characteristics (e.g., tumor stage) that are unique to an individual patient, and are therefore perceived as more relevant than generic, non-personalized risks [14,15]. Even though personalized side-effect risks will likely become increasingly important and common in clinical practice [13], guidelines for *how* healthcare professionals (HPs) can best communicate them to patients are lacking [16,17]. Which message formats do HPs currently use for explaining personalized risks, for instance via words-only, numerical, or graphical formats? Do HPs disclose uncertainty around the personalized risks, and if so, which type(s) and how? Furthermore, it is currently unclear how patients perceive personalized side-effect risks and uncertainty, and also whether, how, and why they use such risks during treatment decision-making [18]. It is crucial to study, as previous research has shown that personalized risks may impact patients' risk perceptions and medical decisions [19–21], which could even depend on how they are communicated [15,22].

Here, we explore the communication of personalized risks of urinary incontinence in the context of PCa treatment decision-making. We focused on the Continence PREDiction tool (CPRED) that predicts the personalized risks of urinary incontinence 6-months post-RARP, based on clinical characteristics [23]. Both NPs and urologists in the Netherlands Cancer Institute (NCI) are currently using CPRED during consultations with patients [19], thereby making it a suitable context for observing the actual communication of personalized risks to newly diagnosed patients. The aim of this study was to investigate how HPs communicate personalized side-effect risks (i.e., urinary incontinence) to PCa patients during consultations, and to explore how these patients, in turn, perceive and use their personalized side-effect risk during treatment decision-making.

2. Methods

2.1. Design

This study consisted of an observational study of audiotaped consultations between HPs and patients and semi-structured interview study with patients. This design was inspired by Engelhardt and colleagues [26], who primarily focused on observing the disclosure of different types of uncertainty during doctor-patient consultations in the context of discussing the outcome of the prediction model "Adjuvant online", and subsequently explored patient perceptions during semi-structured interviews. Here, we extended this approach by not only assessing how HPs communicate uncertainty around personalized risks, but also which message format they used, and how they explained the risk outcomes to their patients. The study protocol was reviewed by the Institutional Review Board of the NCI (IRBd20–285) and was exempted from medical ethical review, according to the Dutch Medical Research Involving Human Subjects Act (WMO). Before the recording/interview, all patients signed written informed consent.

2.1.1. Patient sample

Between December 2020 and March 2021, newly diagnosed patients with localized PCa from the NCI, eligible for RARP as a treatment option and fluent in the Dutch language, were recruited by the NP at the start of their consultation in which information was given about the available treatment option(s). Patients with metastatic PCa were excluded. We aimed for a total of 30 patients, distributed equally among the three CPRED categories (low, intermediate, and high).

2.1.2. Personalized risk of treatment side-effect

The CPRED model was used to determine the personalized risk of urinary incontinence after RARP for each individual patient [19,23]. CPRED predicts the chance of full recovery of urinary incontinence (as defined by the International Consultation on Incontinence Questionnaire-Short Form [24]) based on the preoperative membranous urethral length (MUL) and the inner levator muscle distance (ILD), which are derived from an MRI of the patient's prostate in an earlier clinical examination. Longer MUL and shorter ILD predict higher chance of continence recovery [23]. During the multidisciplinary team consult, the parameters are entered into the prediction model, which produces a CPRED score consisting of a percentage describing the chance of continence recovery (i.e., no diaper or inlay use and no involuntary urine loss) within 6 months after RARP, with higher CPRED scores indicating higher chances of recovery [19,23]. We distinguished three CPRED risk categories: high (0–40%), risk (41–60%), and low (61–100%) [19].

2.2. Procedures and data collection

2.2.1. Consultations

Each patient had two consecutive consultations on the same day (standard procedure): one with the NP, followed by one with the urologist. In both consultations, patients were given information about the outcome of the multidisciplinary team consult (in which the patient was not a part of), the available treatment option(s), and associated risks of side-effects including their personalized CPRED score. In case a patient considered radiotherapy, he could schedule a meeting with the radiologist on that same day. Note that these radiation oncology consultations were not part of the current study and were therefore not recorded. Both NPs and urologists recorded their consultations themselves using an Olympus VN-541PC voice recorder, and they were explicitly instructed to perform their consultation as usual. Patients were told that the study aimed to investigate information provision during consultations about treatment options. The concepts of personalized side-effect risks and CPRED were not introduced. After the second consultation, patients either made a decision about treatment together with their urologist, or they called the urologist at a later moment to jointly make a final decision about treatment.

2.2.2. Patient interviews

After a patient had made a final treatment choice, he was interviewed by RV. On average, these interviews were held 20 days after the consultations ($SD = 11$ days), but they were always scheduled between a patient's final treatment choice and the actual treatment. Due to the COVID-19 situation, interviews were held via telephone, which were recorded using an Olympus VN-541PC voice recorderThe interview protocol started with questions about patients' general experience with the consultations, followed by questions about perceptions of their personalized CPRED score, uncertainty around CPRED, and the role of CPRED in their decision were asked (for the full interview protocol, see Supplementary Material A). After the interview, we assessed patients' subjective numeracy skills using the Dutch version of the Subjective Numeracy Scale [15,25].

2.3. Coding and analyses

2.3.1. Consultations

Consultations were analyzed directly from audio. All fragments in which either the NP and/or urologist communicated a patient's CPRED score were identified, marked, and analyzed using a predefined code scheme (Supplementary Material B). This code scheme was based on research on communicative aspects of patient decision aids for communicating risks [7–9] and on a related observational study by Engelhardt and colleagues [26]. We first coded the *message format* that was used to convey the CPRED score. If verbal information was used, we coded whether this was an absolute and/or a relative risk description. If numerical information was used, we coded whether percentages and/or natural frequencies (e.g., "10 out of 100 patients like you") were used, and whether these numerical estimates were presented as absolute and/or relative risks. We then coded how the CPRED score was *explained* to patients, by focusing on the disclosure of the CPRED model and its predictor variables, the period over which the CPRED scores applied, the defined group (reference class) for which the CPRED scores applied, and the emphasis on the personalization of the risk. Finally, using the coding scheme from [26], we coded which types of *uncertainty* around CPRED were disclosed, focusing on aleatory uncertainty (i.e., unpredictability of single events) and epistemic uncertainty (i.e., imprecision of risk estimates and their applicability to a specific patient). Two independent raters (RV and a research assistant) coded the same five (10%) consultations, and the inter-rate agreement was high (87%). Any discrepancies were resolved in consensus meetings. As the agreement between coders was good, one rater (RV) only coded the remaining consultations. All coding analyses were performed using Microsoft Excel.

2.3.2. Patient interviews

Interviews were audio recorded, transcribed verbatim, and coded using a deductive thematic analysis procedure within an essentialist/realist framework [27,28]. First, three researchers (RV, SP, and EK) familiarized themselves with the qualitative data by independently reading the interview transcripts, taking notes, and marking ideas for coding. Based on these insights, as well as the study objectives, interview protocol, and interview content, RV systematically coded key features of each transcript using MAXQDA software [29], and collated these into potential themes, which, in turn, were refined and relabeled where necessary through discussions with SP and EK. Finally, RV defined and refined each theme and generated the report by selecting illustrative extracts, which were translated into English.

3. Results

3.1. Patient and consultation characteristics

Thirty-four eligible patients were asked to participate in the study and 27 agreed to participate (79%). Of these patients, all consultations with their NP were audio taped successfully. However, for three patients, their consultation with the urologist was not audio taped by accident, bringing the total number of recorded consultations to 51. Patients were on average 66 years old (range: 47–78) (Table 1). Most of the patients opted for RARP as a final treatment option. Urologists and NPs discussed the personalized risk in 50 consultations (98%). For one consultation, the risk was not discussed because the patient already opted for active surveillance.

Table 1
Patient ($n = 27$) and consultation ($n = 51$) characteristics.

Patient characteristics	*n*	%
Age at time of interview, mean (SD)	66.4 (7.8)	
< 50 years	1	4
50–59 years	5	18
60–69 years	9	33
> 70 years	12	44
Education		
Primary/secondary school	6	22
Practical education	8	30
College/applied university	5	18
University	8	30
Gleason score		
6	8	30
7	18	66
8	1	4
Continence PREDiction (CPRED) score		
Low (0–40%)	9	33
Intermediate (41–60%)	8	30
High (61–100)	10	37
Initial treatment preference		
Radical prostatectomy	12	44
External beam radiotherapy	2	8
Brachytherapy	7	26
No preference	6	22
Final treatment choice		
Radical prostatectomy	15	56
External beam radiotherapy	6	22
Brachytherapy	4	15
Active surveillance	2	8
Work situation		
Work	9	33
Ill (insurance) / partial work	2	8
No work/retired	16	59
Marital status		
Married	17	62
Not married / partner living together	8	30
Partner not living together / no partner	2	8
Children		
Yes	19	70
No	8	30
Subjective numeracy, mean (SD)	**4.79 (0.87)**	
Lower numeracy (SNS ≤ 4)	6	21
Higher numeracy (SNS ≥ 4)	21	79
Consultation characteristics		
Duration of consultations in minutes, median (range)	21 (6–42)	
Treatment discussed during consultation		
Radical prostatectomy	51	100
External beam radiotherapy	51	100
Brachytherapy	27	53
Active surveillance	13	25

3.2. Consultations: current practice for communicating personalized side-effect risks

Table 2 displays how many times different aspects occurred during the consultations, including exemplar quotes. The personalized risk of urinary incontinence was typically communicated via a combination of words and numbers (70%), and occasionally via words-only (16%) or numbers-only (14%). When risks were communicated via numbers, HPs always communicated absolute risk statistics using percentages, which were sometimes combined with natural frequencies (19%). The reference class was mentioned in only 20% of the consultations, and the lack of this led to ambiguous statements (e.g., "*We think that you will have full urinary control for 98%*") related to whom the risk refers to (e.g., X percent of the time versus X percent of men like you). When risks were communicated via words, HPs often used absolute verbal descriptors of the risks (e.g., *"That chance is very small"* or *"That's a plausible risk"*), or verbal labels to indicate whether the risk is good or bad (e.g., *"That's not very favorable"* or "*That score is actually quite good, we are really happy with that"*).

In 68% of the consultations, HPs explicitly mentioned that the risk they communicated was personalized and based on a statistical model (e.g., *"We have calculated your personal risk using a model…"*). For instance, as one urologist put it:

> *"For my previous patient, I could say that his risk of urinary incontinence was about 1 or 2%. That man will not experience urinary incontinence, of course. But I cannot say this to you. That is the reason why we calculate these personalized risks, because these risks differ from person to person.*

Table 2
Frequency of communicative aspects discussed by healthcare professionals during consultations with their patients.

Communicative aspect	*n*	%	Exemplar quote (s)
Formats used for communicating personalized risks			
Verbal: absolute risk descriptions	41	82	"That prediction [CPRRED score] is actually not that great." "The chance that you will stay incontinent after the removal of the prostate is very low." "That score is actually quite good, we are really happy with that."
Verbal: relative risk descriptions	10	20	"Your risk of urinary incontinence is higher than the average risk of all men." "For you, this overall risk of urinary incontinence does not make sense, because your risk is lower."
Numerical: percentages	42	84	"We think for 55% that you will be dry 6 months after surgery. So that means that there is a 45% chance that you will lose some urine 6 months after surgery."
Numerical natural frequencies	8	16	"For surgery, the chance that you will recover from urinary incontinence is 28%. So, when you have 10 men like you with the same anatomy and the same length of your membranous urethral, 3 of them will not experience any urinary loss. However, 7 will experience some form of incontinence."
Aspects used for explaining personalized risks			
CPRED predictor: urethra length (MUL)	46	92	"We know that there are two factors that could influence your recovery from urinary incontinence." "That is the membranous urethral length and the distance between the pelvic floor muscles. These two can be measured from the MRI-scan, and in your case, these outcomes are favorable." "Here are some muscles, the pelvic floor muscles. You need to tighten these muscles consciously, and to exercise more consciously to get those muscles on strength. But, there is also another factor and that one related to the length of the urethra. The longer the urethra, the faster you will recover."
CPRED predictor: distance between pelvic floor muscles (ULD)	33	66	
Reference class for which the CPRED scores apply	10	20	"So, you have 10 men like you, with exactly the same anatomy and the same length of the urethra. Of those 10 men, 3 will…"
Time period over which the CPRED scores apply	47	94	"These two factors will give a percentage, and it turns out that we think that the chance that you will not experience any urinary loss 6 months after surgery is 28%."
Degree of urinary incontinence	37	74	"When you'll lose some urine, you'll probably have some drops of urine loss, especially when coughing or sneezing." "That varies quite a lot. In the beginning you'll lose some more urine, but at a certain point you'll only lose some drops or a splash of urine with certain efforts, for instance when getting up."
Reference to (CPRED) prediction model	34	68	"If your urethra is a bit shorter, then you'll have a higher chance of urinary leakage for a longer period of time, and we have calculated this chance for you. We use a sort of calculator for that." "We think that the chance that you will fully recover from incontinence is estimated at around 44 or 45%."
Emphasize that risk is personalized	34	68	"However, I will not provide you with generic risk information, because I have personalized risk information for you. This information is for you, and not for your neighbor or for the next patient. Because for them I will have a different risk." "For my previous patient, I could say that his risk of urinary incontinence was about 1 or 2%. That man will not experience urinary incontinence, of course. But I cannot say this to you. That is the reason why we calculate these personalized risks, because these risks differ from person to person. If I would tell you that your risk is about 15 or 20%, then I am informing you in a way that is too positive."
Types of uncertainty disclosed			
Aleatory uncertainty (first-order)	8	16	"I cannot guarantee that [that will happen] for you." "I cannot say that that [urinary incontinence] will not happen."
Epistemic uncertainty (second-order)	14	24	"The chance that you will recover within 6 months, so that you will be dry, is between 20% and 25%." "But whether it will happen to you individually is also difficult to say. It could just as well be that you will experience no problems at all after this treatment. " "The problem is that we are working with percentages, statistics that apply for the whole group. But for you as an individual it will always be yes or no."

If I would tell you that your risk is about 15 or 20%, then I am informing you in a way that is too positive."

When explaining a patient's personalized risk, HPs almost always referred to the length of the patient's MUL (92%), mostly combined with the ILD (66%). The degree of urinary incontinence was explained in 74% of consultations, and the period over which the CPRED score applied in 94% of the consultations. Finally, in 34% of the consultations some type of uncertainty was disclosed. Aleatory uncertainty was communicated in 16% of the consultations, and epistemic uncertainty in 28% of the consultations. For instance, one urologist explicitly said that the individualized risk only applied at the group level.

"We work with statistics, but for you it will be either yes or no. We work with probabilities that are based on a group of patients. The only thing that matters for you is whether you will experience it or not. That will always be the difference.

3.3. Patient interviews: patient perceptions and use of personalized side-effect risks

Four themes related to patients' perceptions and use of personalized risks were identified (Fig. 1). Exemplar quotes for each subtheme are presented in text and displayed in Table 3.

3.3.1. Theme 1: value of explaining personalized risks

A first theme related to patients' appreciation for explaining their

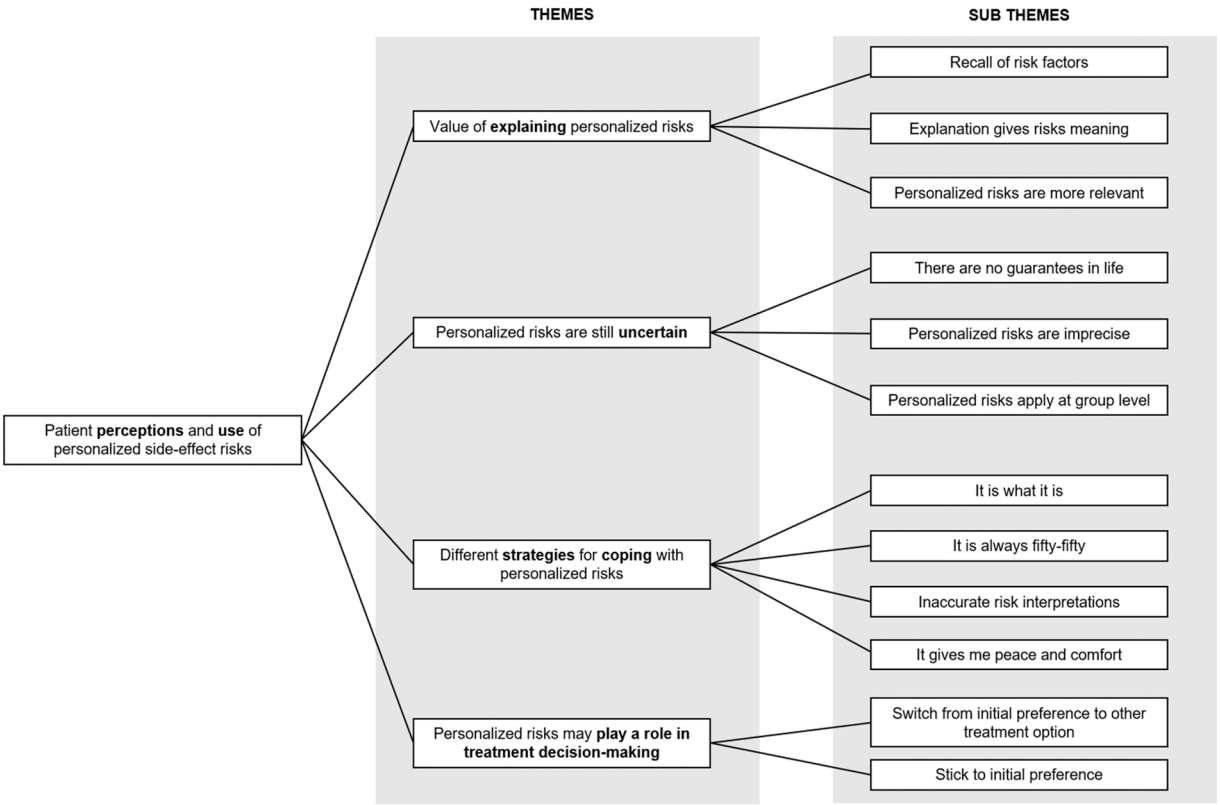

Fig. 1. Overview of the four themes identified in the 27 semi-structured interviews.

personalized risk. Eighteen patients (67%) recalled their CPRED score, and most referred to the MUL and occasionally to the ILD. As one participant put it:

> *"No, I really liked the explanation of the risk, because it became clearer to me. If someone says that my risk of incontinence is 75%, then you will typically forget to ask why that is.* ***But now it was clear to me what the problem was*** *[length of the urethra],* ***so I could better understand the risk****. I liked this style of communication." [P20, CPRED 23%, aged 73, highly numerate]*

Relatedly, patients said that these explanations provided context to the risks and put things into perspective. These risk calculations were based on unique characteristics of patients, which increased perceptions of personal relevance, such as the feeling that the risks really applied to their individual situation (*"It felt really personal"* [P6, CPRED 55%, aged 60, highly numerate]). Patients also suggested to hand out a piece of paper to patients displaying the risk score and its explainable factors.

3.3.2. Theme 2: Personalized risks are still uncertain

A second theme related to patients' perceptions of uncertainty about personalized risks. Regarding aleatory uncertainty, patients mentioned that personalized risks are still unable to predict single events. Patients said that there are no guarantees in life and that their HPs can never say whether something will happen to them in the future, even though the risks are personalized. One patient said that you could just as well be on the other side of the coin:

> *"The doctor made very clear that 86% of the patients will be fine and that the other 14% will not be fine.* ***But you know, these are all statistics****. If you are part of that 14%, then that would be inconvenient, even though that 86% sounds good." [P1, CPRED 86%, aged 72, highly numerate].*

Regarding epistemic uncertainty, patients noticed that personalized risks are still imprecise. They commented that the risks are based on past observations, which can be summarized into a single risk statistic, but will never be exact. *"The more information you gather",* one patient said, *"the more precise the prediction becomes"* [P25, CPRED 27%, aged 76, highly numerate]. Other patients thought that their personalized risk still applied at the group level. These two components of epistemic uncertainty (i.e., imprecision of personalized risk estimates and their inapplicability to a specific patient) were also expressed by this patient:

> *INTERVIEWER: "Do you think that this number is very specific, or could it also be something around…?"*
>
> *PATIENT: "No, around is also fine.* ***It cannot be 100% sure*** *that my score is 25%."*
>
> *INTERVIEWER: "What do you mean exactly with it cannot be 100% sure?"*
>
> *PATIENT: "Well, my risk was about 25%,* ***but it could just as well be 15 or 10%****. It can never be certain,* ***because every human being is unique****." [P24, CPRED 25%, aged 57, less numerate]*

3.3.3. Theme 3: Different strategies for coping with personalized risks

The third theme related to patients' different strategies for coping with and interpreting their personalized risks. There were patients who were quite attached to their risk, which gave them feelings of peace and comfort, or could serve as an indication of what could happen in the future. However, other patients took their risk for granted and mentioned that one cannot do that much about it ("It is what it is"). Others tried to simplify their risk, by translating the probability outcome into a fifty-fifty outcome (i.e., it will happen, or it will not). As this patient put it:

> *"Well, in the end it's about you and whether you will experience it.* ***So, then it will be reduced to a personal dichotomy, eh, yes or no****. So yeah, this is how probabilities work, and we will never know in advance how it turns out for you". [P3, CPRED 48%, aged 78, highly numerate]*

Table 3
Exemplar quotes of all subthemes during the semi-structured interviews with patients.

Theme	Subtheme	Exemplar quote (s)
Value of explaining personalized risks	Recall of risk factors	"Yes, the doctor gave me a percentage and said that my urethra was too short. It would have been better if I would have had a longer urethra. But he said there is nothing I can do about that, because it is just the way how I am built physically." [P9, CPRED 44%, aged 57, highly numerate]
		"They looked at my anatomy, like how my body was built. It has something to do with the pelvic floor and the length of your urethra…I think that was useful, because it was based on my anatomy. Very clear and pleasant." [P6, CPRED 55%, aged 60, highly numerate]
	Explanation gives risk meaning	"Yes, in a consultation some information can be put into perspective. If you receive [generic] risks in a booklet, that is a bit too confronting, like this is it. But when you have a conversation about it, then that personalized risk can be explained … In the end I was quite happy with the consultation, because it felt better than after reading the booklet with the generic risks." [P21, CPRED 28%, aged 47, highly numerate]
	Personalized risks are more relevant	"Yes, they explained that [CPRED score] for my specific situation, like based on my data." [P10, CPRED 98%, aged 66, highly numerate]
Personalized risks are still uncertain	There are no guarantees in life	"The doctor made very clear that 86% of the patients will be fine and that the other 14% will not be fine. But you know, these are all statistics. If you are part of that 14%, then that would be very inconvenient, even though that 86% sounds good." [P1, CPRED 86%, aged 72, highly numerate]
	Personalized risks are imprecise	"Well, if they say that out of 100 people 31 will experience something, that could just as well be 30. With that respect, I have no idea how accurate those studies are. But so far, I always had a pure feeling about the percentages that I received." [P27, CPRED 67%, aged 68, less numerate]
	Personalized risks apply at group level	"That [personalized] risk estimate applies to the entire population in that particular study. It does not say anything about you as an individual…It says something about what they have seen in and experienced with thousand other patients, but that number does not say anything about me…every human body is unique." [P22, CPRED 94%, aged 75, highly numerate]
	It is what it is	"No, these are just the facts, you cannot hide them. And you shouldn't do that anyway…You should accept, it is what it is. I you want to get treated for the problem, there are always risks. You can't rule that out. You need to face it." [P25, CPRED 27%, aged 76, highly numerate]
		"You know, you need to choose between two evils. It [urinary incontinence] is not comfortable, but having cancer is way worse. So, if you want to get rid of it [cancer], then you need to accept that risk. I may be very sober, but also realistic." [P11, CPRED 98%, aged 59, less numerate]
	It is always fifty-fifty	"Well, if you have a risk of 50%, then it's easy. Then is either yes or no." [P24, CPRED 25%, aged 57, less numerate]
	Inaccurate risk interpretations	"The doctor said the degree of incontinence will be about 60%, so yeah we discussed that." [P9, CPRED 44%, aged 57, highly numerate]
	It gives me peace and comfort	"I find it [CPRED score] all reassuring. Because you never want to be that exception who gets something. But I don't think those percentages are weird. I think they are important." [P27, CPRED 67%, agreed 68, less numerate]
		"Well, if you say there is a 30% chance of something, then you get something different. If the risk is below 5%, then I think is sounds more positive. That will give me some reassurance." [P7, CPRED 80%, aged 71, highly numerate]
Personalized risks may play a role in treatment decision-making	Switch from initial preference to other treatment option	PATIENT: "Yes, after 6 months, the chance that I would recover [from urinary incontinence] was 12%." INTERVIEWER: "What were your thoughts at that moment?" PATIENT: "Well, I'm 52 years old, so I will not take that risk. I had two weeks to think about my decision, but, I did not have to wait so long. So, I immediately called the hospital and told them that I wanted radiotherapy." [P17, CPRED 12%, aged 52, less numerate]
	Stick to initial preference	"It had something to do with the urethra, which was too short, and then the risk of incontinence was above average. However, I didn't want surgery anyways, so this [low CPRED score] was added to that [line of reasoning]." [P18, CPRED 43%, aged 71, highly numerate]
Different strategies for coping with personalized risks		

In contrast, others were relieved that their own personalized risk was not close to fifty percent but close to zero or one hundred percent, which facilitated risk processing.

> *"They expressed that [risk of incontinence] in a percentage, and for me that was 90%. Honestly,* ***I was quite happy with that one, because it was such a clear outcome****. If it would have been fifty-fifty, then you really need to think about it." [P2, CPRED 11%, aged 72, highly numerate]*

Six patients (22%) had inaccurate risk interpretations by assuming that the risk referred to the degree of urinary leakage.

> *"Yes, but after 6 months there will be* ***about 80% little or no urinary leakage****". [P7, CPRED 80%, aged 71, highly numerate]*

3.3.4. Theme 4: personalized risks may play a role in treatment decision-making

The fourth theme indicated that personalized risks may play a role in treatment decision-making. For nine patients (33%), their personalized risk score had a decisive role in their decision-making. These patients received a high or intermediate risk of incontinence (CPRED range: 11%−50%) and therefore switched from RARP (as initial preference) to other treatments.

> *"Yes, that was the main reason, that side-effect [urinary incontinence] after surgery. In a certain situation, my urethra could contribute to being incontinent. 28% continent, and 72% incontinent. This made me to opt for radiotherapy." [P23, CPRED 28%, aged 75, highly numerate]*

Other patients within this group used this personalized risk as a confirmation for excluding RARP as a treatment option in the decision process. Patient who did not use the personalized risks (67%) during treatment decision-making valued reasons such as tumor removal or other side-effects (erectile dysfunction or bowel problems).

4. Discussion and conclusion

4.1. Discussion

Given that personalized treatment information is increasingly available and entering clinical care, we observed how HPs (in a urology setting) communicate personalized risks of incontinence after RARP and how patients perceive and use these numbers in their treatment decision-making. Evaluation of audio-recorded consultations revealed that HPs often explained the risk by discussing key factors of the prediction model that contributed to patients' personalized risk. Analysis of interview data showed that patients appreciated personalized side-effect risks and their explanations, which helped them make sense of their own risk data and perceive them as relevant. HPs often used a combination of words and numbers to convey risks; If numbers were used, HPs always used percentages and, in a few instances, natural frequencies. When integrating the observational data with the interview data, some patients (22%) misinterpreted these percentage risk score, by assuming that they would experience urinary leakage in X percent of the time. Therefore, our study supports the recommendation of using natural frequencies for communicating personalized risk estimates [30–32], since percentages do not always specify the reference class or population for whom the personalized risks apply [33]. Finally, HPs hardly disclosed uncertainty around personalized side-effect risks.

For one-third of the patients their personalized side-effect risk of urinary incontinence may have played a role in their treatment choice, which aligns with previous research conducted in a prospective (but not randomized) setting [19]. These patients typically opted for RARP as a preferred treatment choice before the consultation, and either switched to another option (due to a relatively less favorable personalized risk) or sticked to RARP as initial preference (due to a relatively favorable personalized risk). Other patients within this group used their personalized side-effect risk as a confirmation for excluding RARP. There were also patients who did not use their personalized risk of urinary incontinence and valued other reasons such as tumor removal (especially with the thought that radiotherapy would still be possible), or put more weight on side-effects such as erectile dysfunction or bowel problems [34]. These findings are consistent in line with previous findings that most (but definitely not all) patients value and want personalized risk information about treatment outcomes [14,18].

An important observation was that HPs typically communicated the personalized side-effect risk score along with discussing the clinical risk factors (e.g., the patient's urethra length) that contributed to that risk estimate. The interviews revealed that these short explanations helped patients understand why they are at risk and the relationships between risks factors and their personalized side-effect risk. Furthermore, HPs used different contextual strategies for explaining the risk, such as providing verbal evaluative labels whether a score was high or low, or comparative data of the average person's risk. Following theory on information evaluability [35,36], it is challenging for patients to know whether their personalized risk is good or bad, which also makes patients tend to ignore single risk statistics [37]. Although these contextual strategies may be useful for helping patients making sense of personalized statistics [14,38], they can also unintentionally create emotional meanings that may or may not be useful, and should therefore be used with caution [6,39].

The disclosure of uncertainty around personalized risks was limited and discussed in only one-third of the consultations, which is consistent with related observational studies on predicting and communicating individual disease outcomes in the breast cancer or genetic cancer screening context [26,40]. However, contrary to those studies, aleatory uncertainty (i.e., the fundamental indeterminacy or randomness of future events) was communicated less often by HPs than epistemic uncertainty (i.e., the adequacy, reliability, or credibility of personalized risks). It could be that HPs did not want to overwhelm their patients with uncertainty information or to impair the trustworthiness of the information. However, personalized risks—whether related to treatment side-effects, survival rates, or recurrence rates—are all based on prediction models of (a subset of) population-level data, and hence always yield some form of epistemic uncertainty [6], but these uncertainties were hardly shared with patients. Whether HPs should communicate uncertainty around risks at all is a topic of debate [26,41]. Some scholars are in favor for ethical or transparency reasons [42,43], whereas others believe that uncertainty may lead to undesired psychological responses [44,45]. Despite this limited disclosure of uncertainty by HPs, analysis of the interview data showed that patients still perceived these probabilities as imperfect or inapplicable to individual patients. These perceptions could be explained by the fact that patients do not really experience risks or probabilities, but instead experience single outcomes [41]. That is, even though a patient may receive a risk of, for example, 12% of urinary incontinence, for that patient the outcome eventually happens or it does not happen. This also aligns with patients applying different strategies for coping with and interpreting their personalized risk estimates [46]. To some, personalized risks gave them feelings of peace, comfort, and control [14,47,48], while others tried to simplify their personalized risk by translating the probability score into a fifty-fifty outcome (i.e., it will happen, or it will not), which could also mean "don't know" [49].

Some limitations need to be addressed. Our study was mono center, which means that our observations provide a snapshot of how personalized risks are being communicated in a specific clinical setting. Although most of our findings corroborate with similar observational studies [26,40], more observational research is needed in other clinical contexts with larger cohorts and a diverse sample of HPs. Furthermore, we focused on the communication of a specific treatment outcome (i.e., urinary incontinence) and ignored other risks such as erectile dysfunction that were discussed by the NPs and urologists, and we also did not observe radiation oncology consultations. Finally, we recorded two

follow-up consultations with the NP and urologist, which means that patients received their personalized risk and explanation twice. Note that, our focus was not on comparing both types of consultations with each other, but rather on getting general insights into current practices of HPs in their communication of these risks.

4.2. Practice implications

We believe that our findings have three broad clinical implications. First, we recommend HPs to move beyond the individualized risk estimate and put some effort in explaining what role each risk factor plays in determining the risk, which may help patients better understand why they are at risk and recall their own estimate. Second, patients may use personalized risks in their treatment decision-making, which highlights the need for training HPs in clearly communicating these risks in the context of SDM [50]. We believe that some general risk communication techniques can be easily practiced during clinical practices such as the use of natural frequencies instead of percentages [6], but we are also aware that tasks such as communicating different types of uncertainty demand more training [13]. Third, our results are relevant for those developing decision aids that are drawing on medical or patient reported outcome data, and who are facing similar challenges regarding the reliability, accuracy, and credibility of personalized risks. It remains for future research to addresses these challenges, and to investigate how best to help patients translate personalized risks and uncertainty information into better informed decision-making [13].

4.3. Conclusion

In conclusion, while this study demonstrates the value of personalized risk information during shared decision-making about treatment, it also emphasized that risk communication should move beyond providing patients with just specific and precise numbers. Providing contextual information by explaining how personalized risks are determined may help patients understand and recall those. Given that patients may use personalized risks in their treatment decision-making highlights the need for skills training for HPs in clearly communicating these risks.

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CRediT authorship contribution statement

Conceptualization; All authors, Data curation; RDV, CNT, HGvdP, Formal analysis; RDV, SCP, EJK, Funding acquisition; SCP, EJK, LVvdP, Investigation; All authors, Methodology; All authors, Project administration; RDV, CNT, Resources; RDV, CNT, HGvdP, LVvdP, Software; RDV, CNT, Supervision; SCP, HGvdP, LVvdP, EJK, Visualization; RDV, Roles/Writing – original draft; RDV, Writing – review & editing; All authors.

Declaration of conflicting interest

The authors declare no conflict of interest. I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.pec.2022.04.017.

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